Exploring the relationship between disease-related knowledge and health risk behaviours in young people with congenital heart disease

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Abstract

Background. In order to prevent cardiac complications, young people with congenital heart disease (CHD) should conduct heart-healthy behaviours. Therefore, they are assumed to have a good understanding of their disease. However, empirical data on the relationship between disease-related knowledge and health behaviours in this population is lacking.

Aims. This study aimed (i) to describe the health risk behaviours of young people with CHD; (ii) to describe their level of disease-related knowledge; and (iii) to explore the relationship between the level of disease-related knowledge and health risk behaviours.

Methods. Data were collected in 429 young people with CHD. Health risk behaviours were assessed using the Health Behaviour Scale for CHD and the Baecke questionnaire. Disease-related knowledge was evaluated using the Leuven Knowledge Questionnaire for CHD. An overall health behaviour risk score, a total knowledge score and eight thematic knowledge subscale scores were calculated. Eight relationships between knowledge and health risk behaviours were tested.

Results. Patients presented moderate to good overall health behaviour. Disease-related knowledge was found to be relatively poor. Furthermore, better understanding of endocarditis was significantly associated with the performance of annual dental visits.

Conclusions. This study was the first to explore the relationship between disease-related knowledge and health risk behaviours in young people with CHD. Little evidence, however, was found to support this relationship. Additional studies are needed to evaluate the effectiveness of other strategies altering the health-compromising behaviours of these patients.

Introduction

Many patients with congenital heart disease (CHD) remain at risk for developing cardiac complications. Therefore CHD is often considered to be a chronic condition requiring life-long follow-up [1]. To optimize long-term outcomes, afflicted patients should adopt health-promoting behaviours [1-5] comprising appropriate engagement in physical activities; healthy dietary habits; safe sexual activities; the use of appropriate birth control methods; and avoidance of substance use [6].

Research in general populations demonstrated that certain behaviours enacted during adult life often have their roots in adolescence [7-9]. Therefore supporting patients in adopting health-promoting behaviours at an early stage of life is warranted. However, previous studies have demonstrated that adolescence is a vulnerable period characterized by experimental behaviours [10, 11]. Furthermore, it has been demonstrated that the prevalence of unhealthy behaviours, such as the use of alcohol and tobacco, may increase from adolescence through young adulthood [12-15]. Hence, nursing interventions should pay sufficient attention to and target health behaviours of young people with CHD.

Currently, few studies have assessed health behaviours in young people with CHD [13, 16-19] reporting that about one-fourth to half of young people with CHD displayed substance use during the past month [13, 16, 17]. Furthermore, only a small proportion of patients conducted excellent oral hygiene which may increase the risk for developing infective endocarditis [13, 16, 18]; and one-third of adolescents with CHD did not reach the recommended level of physical activity [19].

To establish a heart-healthy lifestyle, young people with CHD are assumed to have a good understanding of their heart condition, treatment and preventive measures [20, 21]. Studies, however, found that patients have poor to moderate understanding of their heart condition [22-29], hereditariness of CHD [2, 30], reproductive issues [23, 24], safe levels of physical activity [23, 24, 31] and aspects of self-care activities preventing endocarditis [23, 26, 27, 29, 32]. The level of knowledge concerning the treatment regimen varied from poor to adequate [23, 24, 26, 27, 29].

In order to improve the level of knowledge, structured education programs are recommended [33-35]. One study has recently demonstrated that a structured education program was an independent determinant of higher levels of knowledge [36]. However, the final goal of patient education should be to increase the likelihood of patients engaging in a heart-healthy lifestyle and, ultimately, in an improved

quantity and quality of life [37]. Empirical evidence supporting the hypothesis that higher levels of knowledge are related to lower levels of health risk behaviours in this population is currently lacking.

Therefore, this study aimed (a) to describe the health risk behaviours of young people with CHD; (b) to describe their level of disease-related knowledge; and (c) to explore the relationship between the level of disease-related knowledge and health risk behaviours.

Methods

Study population

As part of the i-DETACH project (Information technology Devices and Education programme for Transitioning Adolescents with Congenital Heart disease), data on health risk behaviours and disease-related knowledge were collected using a four-wave descriptive longitudinal study, spanning three years. Eligible patients were selected from the database of paediatric and congenital cardiology of the University Hospitals Leuven, Belgium. Patients were included if they met the following criteria: confirmed diagnosis of CHD, defined as 'structural abnormalities of the heart and/or great intrathoracic vessels that are actually or potentially of functional significance'[38]; aged 14-18 years at the start of the study on October 22, 2009; last cardiac outpatient visit at our tertiary care centre performed ≤5 years ago; being able to read and write Dutch; and the availability of valid contact details. Patients were excluded if they had cognitive and/or physical limitations that inhibit the patient from filling out questionnaires; if the patient previously underwent heart transplantation; and if patients and/or their parents did not consent to participate. For the present study, data collected at the first (T1) and fourth (T4) measurement point of the i-DETACH project were analysed.

At T1, 429 patients participated (response rate of 86%) and 338 patients participated at T4 (response rate of 77%). A total of 327 patients participated both at T1 and T4. The sample at T1 consisted of 229 (53.4%) men with a median age of 16.3 years (Q1=15.3; Q3=17.3). In this sample, 174 (40.6%) patients had a mild; 204 (47.6%) patients had a moderate; and 51 (11.9%) patients had a complex heart defect. Two hundred (46.6%) patients underwent at least one cardio-surgical intervention. Detailed demographic and clinical characteristics of this sample have been previously published in a related article(39). Patients at T4 did not differ on sex (χ^2= 0.14, p=0.71), complexity of

primary CHD diagnosis (χ^2= 0.35, p=0.84), and the proportion of patients having undergone cardiac surgery (χ^2= 0.20, p=0.65), from patients participating at T1. However, differences were found on the current level of education (χ^2= 28.8, p<0.001), and as hypothesised due to the longitudinal character of this study, patients at T4 were significantly older (t=-29.24, p<0.001).

Procedure

At each measurement point, patients received a set of questionnaires, an information letter, an informed consent and a pre-stamped and addressed return envelope by surface mail. To enhance the response rate, a modified Dillman's approach was used [40]. The study protocol was approved by the Institutional Review Board of the University Hospitals Leuven, Belgium (Belgian number B32220096259) and was performed in accordance to the 2002 Declaration of Helsinki.

Variables and measurement

Demographic data were collected using a self-reported questionnaire. Clinical variables were collected from patients' chart review. Health risk behaviours were assessed using the Health Behaviour Scale-CHD (HBS-CHD) and the Baecke questionnaire. The HBS-CHD is a self-report instrument consisting of 22 items covering three important components of health behaviour in patients with CHD i.e. (a) the use of alcohol, (b) the use of tobacco and illicit drugs; and (c) oral hygiene. Evidence was provided for good psychometric properties of this scale(12). To evaluate the engagement in physical activities, we used a modified version of the Baecke questionnaire(41). The Baecke questionnaire comprises three dimensions of physical activity: (a) at work, (b) during sports activities, and (c) during leisure time. Since our study comprised mainly school-attending adolescents, we excluded the survey items assessing the level of physical activity during work time. The Baecke questionnaire was found to be a standard of reference validated against different objective measurement techniques [42, 43].

The level of disease-related knowledge was assessed using the Leuven Knowledge Questionnaire for CHD (LKQ-CHD). The revised version consists of 31 or 34 items for men or women, respectively. This questionnaire covers five domains: (a) knowledge of the heart defect and treatment; (b) knowledge of the prevention of complications; (c) knowledge of physical activities; (d)

knowledge of sexuality and heredity; and (e) knowledge of contraception and pregnancy planning. A recent study provided evidence for content and concurrent validity of the LKQ-CHD in adolescents with CHD [24].

Full data on the different components of health risk behaviours are available for 419 to 429 patients at T1, and for 254 to 338 patients at T4. Full data on level of knowledge are available for 429 patients at T1 and 338 patients at T4.

Statistical analysis

The use of the HBS-CHD and the Baecke questionnaire allowed calculating three health behaviour risk scores. First, we calculated a 'substance use risk score', ranging from 0-3, based on the presence of (a) binge drinking at least monthly, (b) the use of ≥1 drug(s) once a month or more, and (c) smoking cigarettes. Second, a 'dental hygiene risk score', varying between 0-3, was calculated based on the reporting that (a) the patient did not have an annual visit to a dentist, (b) did not brush teeth on a daily basis, and (c) did not floss teeth. Finally, an 'overall health behaviour risk score' was computed based on the individuals' respective substance use risk score, dental hygiene risk score, and the absence of participation in physical activities. This latter score ranged from 0-7. All these risk scores were transformed to a scale from 0-100, with a higher score representing worse health behaviour. Furthermore, the Baecke questionnaire enabled us to calculate a 'sport score' and a 'leisure time index', using established algorithms [41].

After evaluating the correctness of patients' answers on the LKQ-CHD, a total knowledge score ranging from 0-100 was calculated by computing the number of correct answers divided by the number of eligible answers, multiplied by 100. Furthermore, eight thematic subscale scores were calculated, representing knowledge on (a) CHD diagnosis, (b) treatment, (c) follow-up, (d) cardiovascular risk, (e) symptoms, (f) endocarditis, (g) physical activity, and (h) reproduction, each comprising 1-9 items. These subscale scores ranged from 0-100 and were calculated by using the same formula as for the overall knowledge score. For both the total knowledge score and the eight thematic subscale scores, a correction for missingness was adopted, enabling the calculation of these latter scores if at least two-thirds of scale items were filled out. Knowledge scores were evaluated using the

criteria defined by Moons et al.[2]: < 50% correctness = a poor level of knowledge; 50-80% correctness = moderate level of knowledge; and > 80% correctness = good/adequate level of knowledge.

Descriptive statistics for nominal data were expressed in absolute numbers and percentages. Ordinal data were presented as medians and interquartile ranges. Continuous data were presented as means and standard deviations (SDs) if data were normally distributed. The relationship between the total knowledge score and the overall health behaviour risk score was tested using the Spearman's rho correlation coefficient. Associations between the thematic subscales scores and the presence of risk behaviours (yes/no) were evaluated using the Mann-Whitney *U*-test. All tests were two-sided. Although the present study was exploratory, the false discovery rate method of Benjamini[44] was used to correct for multiple testing. The expected number of type I errors was kept below 5%, and adjusted *p*-values were denoted as *q*-values. Hence, the level of significance was set at $q<0.05$. Statistical analyses were performed using SPSS, version 20.0 (SPSS Inc., Chicago, Illinois, USA).

Results

Health risk behaviours

The mean overall health behaviour risk score was 17.5 (SD=14.4) at T1 and 28.1 (SD=14.0) at T4 representing moderate to good overall health behaviours. This overall risk score encompasses three major components: substance use, oral hygiene and physical activity. The substance use risk score was 6.59 (SD=18.15) at T1 and 14.8 (SD=18.8) at T4. A more detailed analysis demonstrated that 241 (56.2%) patients at T1 and 198 (75.0%) at T4 consumed alcohol from time to time; and 34 (7.6%) engaged in binge drinking at least monthly at T1 and 59 (17.5%) at T4 (**Table 1**). Furthermore, 7.3% (T1) to 9.4% (T4) of our sample smoked cigarettes occasionally or regularly; and 5.1% (T1) and 8.5% (T4) used some kind of (illicit) drugs over the past year. The most frequently used drugs were cannabis, followed by sleeping pills, sedatives or tranquilisers.

The dental hygiene risk score was 26.7 (SD=22.4) at T1 and 27.0 (SD= 24.0) at T4, 10% (T1) to 17% (T4) of our patients did not have a dental visit over the past year (**Table 2**). Dental flossing was most rarely performed by patients as 64.9% (T1) to 61.3% (T4) never flossed their teeth. Finally, 44.4% (T1) to 42.5% (T4) brushed their teeth less than twice a day.

In our sample, 24.5% (T1) to 33.0% (T4) did not engage in any sport (**Table 3**). The median sport score was 4.06 at T1 and 2.99 at T4.The median leisure time index (scale range: 0 to ∞) was 2.75 at T1 and 3.0 at T4.

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Level of disease-related knowledge

The mean total knowledge score was 44.7 (SD=15.0) at T1 and 50.8 (SD=17.0) at T4, representing a poor to moderate level of knowledge. For the thematic subscales, the mean scores ranged from 15.0 (SD=35.7) for symptom recognition to 66.1 (SD=26.4) for physical activity at T1 and from 28.0 (SD= 45.2) for symptom recognition to 70.4 (SD= 25.3) for physical activity at T4. More specifically, patients displayed poor levels of knowledge on five thematic subscales: (a) knowledge about CHD diagnosis, (b) cardiovascular risk factors, (c) symptoms of deterioration, (d) endocarditis, and (e) reproductive issues. Furthermore, they displayed moderate knowledge on their treatment regimen; follow-up; and recommended level of physical activity (**Table 4**).

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Relationship between the health risk behaviours and the level of disease-related knowledge

Eight potential relationships between knowledge scores and health behaviour risk scores, based on clinical experience and hypotheses, were tested. At T1, a significantly higher level of endocarditis knowledge was found in patients who presented for annual dental visits, as compared to those without annual dental visits (U=5968.5, q=0.008). The same relationship was found to be significant at T4 (U=3772.0, q=0.048). Furthermore, higher total knowledge scores were significantly associated with lower levels of overall health risk behaviours (rho= -0.167, q=0.016) (**Table 5**).

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Discussion

Adolescence is a critical period for patients with CHD since health-related behaviours are established during this developmental stage [47]. Furthermore, it has been demonstrated that health risk behaviours enacted during adolescence may increase during emerging adulthood [12,48] and may predict future unhealthy behaviours[7-9]. Therefore, it is important to support patients in adopting health-promoting behaviours at an early stage of life in order to prevent engagement in unhealthy behaviours during adulthood.

Nurses traditionally focus on improving lifestyle in patients with CHD through educational interventions [49]. Due to the fact that the provision of patient education is a time-consuming activity, these interventions should be effective, not only in terms of increasing patients' knowledge [36], but also in terms of promoting healthy behaviours. To our knowledge, no study has previously assessed the relationship between disease-related knowledge and health risk behaviours in young people with CHD.

The present study explored eight potential relationships between knowledge and behaviour in young people with CHD. We demonstrated that the knowledge of endocarditis-related issues was positively associated with having annual dental visits. In addition, higher total knowledge scores were significantly associated with performing less health risk behaviours. Despite the relatively weak and few associations, these findings are in line with theories explaining people's behaviours. One model commonly used in social sciences is 'The integrative model of behavioural prediction'[50]. This model suggests that knowledge may not play a major role in explaining variability in behaviour, nor in behavioural intention. In contrast, self-efficacy, the extent to which a person feels capable of effectively performing the behaviour, directly influences people's behaviour. Therefore, it may be desirable to explore alternative forms of patient education that may enhance self-efficacy and, therefore, could influence behavioural intention. Motivational interviewing is such a technique that has proven to be effective in achieving this goal[51]. This technique could be used aside from the classic form of patient education which has demonstrated to increase the level of knowledge[36].

Even though understanding of potential risks may not directly influence people's behaviour we may not underestimate the role of knowledge. Empirical evidence in patients with cardiovascular

disease has demonstrated that although knowledge alone did not ensure patient compliance, patients could only comply when they possessed a minimal level of knowledge about the disease and healthcare regimen [52,53]. Therefore, we suggest that transition programs which prepare adolescents with CHD for taking responsibility over their own health should include patient education, but also adopt alternative forms of patient education such as motivational interviewing. Doing this, they could promote adequate self-efficacy and knowledge levels. Future studies should explore the effectiveness of this combined strategy.

This study has demonstrated that young persons with CHD generally have a relatively healthy lifestyle and -as demonstrated by a previous study- even healthier than matched controls from the general population [12]. However, our findings suggest that the prevalence of substance use increases when growing older. This observation may be partly explained by the legal drinking age that is set at the age of 16 in Belgium.

Not engaging in any health risk behaviour might be the most desirable endpoint for clinicians. Such zero tolerance, however, may create additional challenges in terms of social acceptance for these young people [6]. Therefore, some tolerance toward experimental behaviours during adolescence might be advocated, as long as such behaviours do not persist and are within clinically acceptable limits. Furthermore, our findings revealed great diversity in the prevalence of health risk behaviours, which is in line with previous research [13,16-19]. First, it was apparent that only a small proportion of our patients performed excellent oral health behaviours, including daily brushing of teeth, dental flossing and annual dental visits. In line with previous studies, 'no performance of dental flossing' seemed to be the most prevalent health risk behaviour [13,18]. This may have major consequences since this unhealthy behaviour has previously been associated with an increased risk for endocarditis [54.] Furthermore, preventive dental habits may even be worse in patients with CHD than in healthy matched controls [12]. This supports the need for additional interventions aimed towards better dental hygiene behaviours. Second, rates of substance use were comparable to or lower than rates reported in previous studies, with alcohol being the most frequently used substance [13,16,17]. Furthermore, a study conducted in the same sample of patients found that substance use is significantly lower in patients with CHD as compared to matched controls [12]. However, since the consequences of alcohol consumption may be

greater for CHD patients than for healthy peers, continuous attention in young people with CHD is required[6]. Furthermore, our study demonstrated that illicit drugs were the least frequently used substance. However, our finding may not entirely reflect illicit drug use because sleeping pills, sedatives and tranquilisers may in some circumstances, i.e. when prescribed, be used legally. Third, although the health benefits of physical exercise have been extensively documented, approximately one-quarter of our sample did not perform any type of physical activity, which is in line with previous research[19,55]. This low level of physical activity might result from misconceptions patients have about safe and desirable levels of physical activity [56].

Regarding the level of disease-related knowledge, we found that patients' knowledge was suboptimal. When comparing our results to previous research, it was apparent that for three out of the eight thematic subscales- knowledge of CHD diagnosis, symptoms of deterioration and follow-up – previous studies consistently reported similarly low knowledge levels [22-29]. However, for the five other thematic subscales, prior research reported variable study results [23, 24, 26, 27, 29, 31] particularly due to a large variability in the research aims, age ranges of included subjects, and assessment tools across the studies. These overall suboptimal knowledge levels may reflect the consequences of the current health care system in which only 0.9% of the healthcare budget is invested in preventive care [57]. More investment in preventive strategies such as comprehensive education programmes is needed if we wish to deliver more empowered and knowledgeable patients.

Methodological issues

The results of the present study must be interpreted with caution due to some methodological limitations. First, since this study was a single-centre study performed in Belgium, generalizability of study results is limited. Second, previous studies have provided evidence to support the content validity and external validity for the LKQ-CHD [2,24]. However, to date, other psychometric properties of this instrument remain unaddressed[24]. Third, health risk behaviours in our patients were measured using the HBS-CHD, an instrument for which evidence was found supporting content validity, external validity, and responsiveness. The stability, however, could not be confirmed based on this initial study [12]. Fourth, since non-paired samples were used in this study the comparison made between

these samples are explorative of nature. The design does not allow drawing conclusions about evolutions over time or individual trajectories. Finally, the associations between knowledge and behaviour, based on cross-sectional data, do not allow us to draw conclusions about the direction of effects. For this purpose, cross-lagged analyses should be performed. Explorative analyses on complete cases provided, however, no evidence for cross-lagged effects.

In contrast to these limitations, this study was, however, the first to calculate thematic knowledge scores. These scores allowed us to more differentially identify and address specific knowledge gaps in young people with CHD. Second, these thematic subscale scores could be linked to specific health risk behaviours and allowed us to explore hypothesized relationships. Third, since one may argue that the importance of some knowledge items may differ between certain subsets of the population, the subscale scores allow professionals to calculate summary scores while taking the relevance of each subscale for a patient's specific condition into account.

Conclusion

This study was the first to explore the relationship between disease-related knowledge and health risk behaviours in young people with CHD. Limited evidence was found to support this relationship. This study found a significant positive association between knowledge on endocarditis and annual dental visits, and a positive relationship between the overall knowledge score and health behaviours. Therefore, clinicians, in particular nurses, should consider adopting alternative forms of patient education, such as motivational interviewing, complementary to the classic form of patient education to ensure both adequate levels of knowledge and self-efficacy. This combination of techniques may consequently facilitate the integration of appropriate health behaviours in our patients. Furthermore, future studies should confirm our findings and investigate if the aforementioned relationships also result in better clinical outcomes.

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Conflict of interest

The authors declare that there is no conflict of interest.

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Implications for practice

- Although health behaviours in young people with CHD are generally good, there is room for improvement.
- Young people with CHD display important knowledge gaps with respect to different aspects of their disease. Therefore, clinicians should perform efforts to increase knowledge levels in their patients.
- Transition programs for patients with CHD should include patient education but should also explore interventions enhancing self-efficacy in these patients. However, the effectiveness of these combined methods should be evaluated.

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Tables

Table 1. Substance use in young people with congenital heart disease

	T1 n (%)	T4 n (%)
ALCOHOL		
Consuming alcohol from time to time	241 (56.2)	198 (75.0)
If yes, how often?		
≤ 1 x per month	101 (41.9)	67 (33.5)
2-4 x per month	129 (53.5)	97 (48.5)
2-3 x per week	10 (4.1)	34 (17.0)
≥ 4 x per week	1 (0.4)	2 (1.0)
If yes, how many glasses do you have on average?		
1-2	117 (48.5)	81 (40.7)
3-4	76 (31.5)	63 (31.7)
5-6	30 (12.4)	37 (18.6)
7-9	10 (4.1)	12 (6.0)
≥ 10	8 (3.3)	6 (3.0)
If yes, how often do you drink six glasses or more on one occasion ?[a]		
less than monthly	207 (85.9)	68 (32.9)
monthly	26 (10.8)	39 (18.8)
weekly	8 (3.3)	18 (8.7)
daily or almost every day	0 (0)	2 (1.0)
never	0 (0)	80 (38.6)
TOBACCO		
Smoking cigarettes occasionally or regularly	31 (7.3)	25 (9.4)
If yes, during the last 30 days, on how many days did you smoke cigarettes?		
1-2 day(s)	3 (10.7)	4 (16.7)
3-5 days	6 (21.4)	2 (8.3)
6-9 days	2 (7.1)	1 (4.2)
10-19 days	5 (17.9)	2 (8.3)
20-29 days	6 (21.4)	7 (29.2)
all 30 days	6 (21.4)	8 (33.3)
If yes, during the last 30 days, on the days you smoked, how many cigarettes did you smoke a day?		
≤1 per day	4 (14.3)	3 (12.5)
2-5 per day	14 (50.0)	10 (41.7)
6-10 per day	6 (21.4)	8 (33.3)
11-20 per day	4 (14.3)	3 (12.5)
> 20 per day	0 (0)	0 (0)
ILLICIT DRUGS		
How often in the last 12 months did you take the following drugs?		
Cannabis		
never	415 (96.7)	249 (94.0)
≤ 1x per month	5 (1.2)	8 (3.0)
2-4x per month	6 (1.4)	2 (0.8)
≥ 2x per week	3 (0.7)	6 (2.3)
XTC[b]		
never	425 (99.8)	263 (100)
≤ 1x per month	1 (0.2)	0 (0)
2-4x per month	0 (0)	0 (0)
≥ 2x per week	0 (0)	0 (0)

Cocaine		
never	425 (100)	263 (100)
Hallucinogenic mushrooms		
never	425 (100)	263 (100)
Speed		
never	423 (99.5)	263 (100)
≤ 1x per month	1 (0.2)	0 (0)
2-4x per month	1 (0.2)	0 (0)
≥ 2x per week	0 (0)	0 (0)
Sleeping pills, sedatives or tranquillizers		
never	420 (98.8)	257 (97.7)
≤ 1x per month	1 (0.2)	2 (0.8)
2-4x per month	2 (0.5)	2 (0.8)
≥ 2x per week	2 (0.5)	2 (0.8)

[a]Binge drinking= drinking ≥6 glasses of alcohol on one occasion[55;56]
[b]Ecstacy

Table 2. Oral hygiene in young people with congenital heart disease

	T1 n (%)	**T4 n (%)**
No visit to the dentist the past year	45 (10.5)	45 (17.0)
If you did not visit the dentist the past year, when did you last go to the dentist?		
never	0 (0)	1 (2.2)
1-2 yrs ago	28 (63.6)	37 (82.2)
2-3 yrs ago	8 (18.2)	6 (13.3)
> 3 yrs ago	8 (18.2)	1 (2.2)
How often do you brush your teeth?		
never	5 (1.2)	1 (0.4)
now and then	27 (6.4)	10 (3.9)
1x per day	155 (36.8)	97 (38.2)
2x per day	221 (52.5)	137 (53.9)
3x per day	12 (2.9)	9 (3.5)
>3x per day	1 (0.2)	0 (0)
How often do you floss your teeth?		
never	272 (64.9)	157 (61.3)
now and then	125 (28.9)	90 (35.2)
1x per day	16 (3.8)	7 (2.7)
2x per day	6 (1.4)	2 (0.8)
3x per day	0 (0)	0 (0)
>3x per day	0 (0)	0 (0)

Table 3. Physical activities in young people with congenital heart disease

Sport	**T1 n (%)**	**T4 n (%)**
Absence of engagement in sport	105 (24.5)	87 (33.0)
If you play sport,		
...how many hours a week?		
<1 hour	20 (6.2)	9 (5.1)
1-2 hour(s)	89 (27.6)	52 (29.5)
2-3 hours	63 (19.5)	41 (23.3)
3-4 hours	48 (14.9)	20 (11.4)
>4 hours	103 (31.9)	54 (30.7)
...how many months a year?		
<1 month	6 (1.9)	1 (0.6)
1-3 month(s)	7 (2.2)	5 (2.9)
4-6 months	20 (6.3)	18 (10.4)
7-9 months	74 (23.5)	53 (30.6)
>9 months	208 (66.0)	96 (55.5)
If you play a second sport,		
...how many hours a week?		
<1 hour	22 (19.0)	15 (23.1)
1-2 hour(s)	50 (43.1)	22 (33.8)
2-3 hours	18 (15.5)	13 (20.0)
3-4 hours	4 (3.4)	5 (7.7)
>4 hours	22 (19.0)	10 (15.4)
...how many months a year?		
<1 month	7 (6.1)	3 (4.7)
1-3 month(s)	15 (13.2)	8 (12.5)
4-6 months	12 (10.5)	12 (18.8)
7-9 months	32 (28.1)	12 (18.8)
>9 months	48 (42.1)	29 (45.3)
Sport-score (median; Q1-Q3)[42]	4.06; 1.74-6.01	3.04; 1.74-5.63
Leisure time		
In comparison with others of my own age I think my physical activity during leisure time is		
much more	31 (7.3)	22 (6.5)
more	67 (15.7)	51 (15.2)
the same	190 (44.5)	137 (40.8)
less	101 (23.7)	93 (27.7)
much less	38 (8.9)	33 (9.8)
During leisure time I sweat		
very often	26 (6.1)	22 (6.5)
often	77 (18.0)	77 (22.8)
sometimes	193 (45.1)	147 (43.6)
seldom	105 (24.5)	82 (24.3)
never	27 (6.3)	9 (2.7)
During leisure time I play sport		
never	30 (7.0)	25 (7.4)
seldom	82 (19.1)	72 (21.4)
sometimes	154 (35.9)	122 (36.3)
often	120 (28.0)	90 (26.8)
very often	43 (10.0)	27 (8.0)
During leisure time I watch television		
never	2 (0.5)	6 (1.8)
seldom	22 (5.2)	49 (14.6)
sometimes	130 (30.4)	134 (39.9)
often	226 (52.9)	133 (39.6)

very often	47 (11.0)	14 (4.2)
During leisure time I walk		
never	53 (12.4)	30 (9.0)
seldom	120 (28.0)	88 (26.3)
sometimes	159 (37.1)	124 (37.0)
often	83 (19.3)	80 (23.9)
very often	14 (3.3)	13 (3.9)
During leisure time I cycle		
never	51 (11.9)	33 (9.8)
seldom	79 (18.4)	94 (28.0)
sometimes	166 (38.7)	117 (34.8)
often	97 (22.6)	67 (19.9)
very often	36 (8.4)	25 (7.4)
How many minutes do you walk and/or cycle per day to and from work, school and shopping?		
< 5 min	35 (8.2)	24 (7.1)
5-15 min	95 (22.2)	70 (20.8)
15-30 min	144 (33.6)	127 (37.8)
30-45 min	88 (20.6)	63 (18.8)
> 45 min	66 (15.4)	52 (15.5)
Leisure time index (median; Q1-Q3)[42]	2.75; 2.50-3.25	3.0; 2.50-3.25

Table 4. Disease-related knowledge in young people with congenital heart disease

Knowledge scores ($\bar{x}$±SD)			**Evaluation knowledge scores[a]**	
	T1	**T4**	**T1**	**T4**
Total knowledge score	44.7 ± 15.0	50.8 ± 17.0	Poor	Moderate
Thematic subscale scores				
1. CHD diagnosis	44.9 ± 41.0	51.6 ± 41.9	Poor	Moderate
2. Treatment	53.0 ± 31.5	58.0 ± 32.1	Moderate	Moderate
3. Follow-up	59.4 ± 29.9	59.2 ± 28.5	Moderate	Moderate
4. Cardiovascular risk	49.3 ± 20.1	46.8 ± 22.2	Poor	Poor
5. Symptoms	15.0 ± 35.7	28.0 ± 45.2	Poor	Poor
6. Endocarditis	41.0 ± 22.4	48.8 ± 24.9	Poor	Poor
7. Physical activity	66.1 ± 26.4	70.4 ± 25.3	Moderate	Moderate
8. Reproduction	19.8 ± 33.3	31.7 ± 37.6	Poor	Poor

[a] Evaluation of knowledge scores according to criteria defined by Moons et al.[2]; (1) <50% correctness= poor knowledge, (2) 50-80% correctness= moderate knowledge; (3) >80% correctness= good knowledge.

Table 5. Relationships between disease-related knowledge and health risk behaviours in young people with CHD

Knowledge	**Behaviour**	***T1 Test statistic (q-value)***	***T4 Test statistic (q-value)***
Total knowledge score	Overall health risk behaviour score	rho=-0.076 (0.312)	rho=-0.167 (0.016)
Cardiovascular risk	Binge drinking	U=5979.0 (0.464)	U=7398.5 (0.354)
Cardiovascular risk	Drug use	U=3647.0 (0.466)	U=3471.0 (0.990)
Cardiovascular risk	Cigarette smoking	U=5569.0 (0.466)	U=2900.0 (0.870)
Endocarditis	No annual dental visit	U=5968.5 (0.008)	U=3772.0 (0.048)
Endocarditis	No daily dental brushing	U=5920.5 (0.519)	U=1057.0 (0.051)
Endocarditis	No dental flossing	U=18525.5 (0.084)	U=13443.0 (0.626)
Physical activity	Absence of physical activity	U=14918.5 (0.466)	U=7332.0 (0.653)